



How States Access and Deploy Data to Improve SUD Prevention, Treatment, and Recovery

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The nation's substance use disorder (SUD) epidemic poses unique challenges for policymakers working to understand and apply data – which often exists in disparate systems – to guide their treatment and interventions. States, localities, and organizations need to access and generate reliable data, not just in health and behavioral health care, but in workforce, criminal justice, social services, and other systems to design successful SUD interventions.

This report describes the uses and limitations of commonly available data sets that can stand alone or be used in conjunction with other data to answer common questions posed by state and local leaders.

The report reviews common data sources that can help state leaders address key issues, such as preventing SUD and diversion of controlled substances, supporting harm reduction, increasing treatment capacity and service delivery, and understanding the needs of vulnerable populations. The report also highlights best practices at the state level, and notes where state strategies can also assist communities in accessing and using data to support local efforts.

Many data sets produced by state and federal agencies have value when used individually, but when data can be shared and presented in new ways, it begins to tell a more comprehensive story of the particular and highly localized impact of SUD across systems and populations.

The State SUD Data Landscape

Policymakers have access to data sets that are collected, compiled, analyzed, and maintained by state and federal agencies and other entities responsible for providing or overseeing services related to the prevention, reduction, or treatment of SUD. The following highlights data sets that are commonly used by state policymakers in their efforts to analyze key SUD indicators.

Individual claims and administrative and programmatic data collected by states:

Individual-level data sets that tie to the unique experiences of one person through a system can help illuminate the ways that individuals and populations seek and use services. This data is often personally identifiable, which requires either consent, legally authorized use, or systematic anonymization that removes identifying characteristics.

Data	Ownership/Maintenance	Content
Medicaid claims and encounter data	State Medicaid agency Medicaid managed care organization	<ul style="list-style-type: none"> • Patient demographic data • Diagnostic/service codes • Service utilization data
Prescription drug monitoring programs (PDMPs)	State licensing boards, public health agencies, or free-standing PDMP agency	Patient and prescriber data related to scheduled prescription drugs
Vital statistics, forensic epidemiology, or medical examiner/coroner reports	State public health or vital statistics agencies	<ul style="list-style-type: none"> • Deceased demographic data • International Classification of Diseases 9-10 codes identifying causes of death • Toxicology reports
Homeless management information systems	State housing or social service agencies	Housing program services and client data, including self-reported diagnoses
Infectious disease data	State public health agencies	Surveillance data on hepatitis B/C and HIV infections
Behavioral health services data	State behavioral health agencies	<ul style="list-style-type: none"> • Non-Medicaid-funded services for SUD delivered by community behavioral health systems or state hospitals • Provider licensure information
Emergency medical systems data	State public health agencies	Overdose response data, including naloxone deployment
Hospital admissions and discharge data	State public health agencies	Overdoses treated in hospital settings and/or discharges coded as overdose-related
Corrections	State and local corrections agencies	Health and behavioral health assessment and treatment data for incarcerated individuals

De-identified state/federal data sets available to researchers, organizations, and the public:

Aggregate data sets can also be helpful to understand system interactions and population trends. These kinds of data are valuable in gauging systemwide behaviors as well as shifts in services, demographics, or activities that indicate the needs of a given region or population.

Data Set	Ownership/Maintenance	Content
All-payer claims databases (APCD)	Independent state or quasi-governmental organizations	Insurance claims from across payer sources
Behavioral Risk Factor Surveillance System (BRFSS)	Centers for Disease Control and Prevention (CDC)	Self-reported health risk factor and health condition data
Census data	US Census Bureau	Self-reported demographic data

National Overdose Report	CDC	Overdose deaths by demographics, states/regions, and substances present
Annual HIV Surveillance Report	CDC	HIV infections by demographics, states/regions, and transmission factors
National Survey on Drug use and Health (NDSUH)	Substance Abuse and Mental Health Services Administration (SAMHSA)	Self-reported substance use, mental health, and treatment services by demographics and state/region

SUD Data Use Cases for State and Community Leaders

The following data use cases and strategies describe how available data can be used, often in innovative ways, to inform and guide state and local policy decisions.

Limit Diversion and Promoting Prevention Use Cases

Prescription opioids are often described as the substances behind the “first wave” of an overdose epidemic that has evolved to now be driven by illicit forms of opioids, such as heroin and fentanyl. In one [study](#), over 80 percent of current heroin users reported that their first experiences with opioids involved diverted prescription pills, suggesting that policy interventions to reduce this diversion should be among state and local leaders’ top priorities. Analyzing available data can help to structure strategies that limit opioid diversion and prevent inappropriate prescribing.

Identify risky prescribing: Forty-nine states and Washington, DC support [Prescription Drug Monitoring Programs](#) (PDMPs) that contain prescriber, dispenser, and patient-level data about controlled substances. Policymakers can use PDMP data to develop baselines that help show geographic and individual prescriber averages, as well as aberrations in prescribing and dispensing patterns. Pennsylvania maintains [public-facing aggregate PDMP data](#) that can be searched at the county level for a range of measures that indicate risky prescribing patterns, such as:

- Number/rate of individuals seeing five-plus prescribers and five-plus dispensers;
- Number/rate of individuals seeing four-plus prescribers and four-plus dispensers;
- Number/rate of individuals seeing three-plus prescribers and three-plus dispensers;
- Morphine milligram equivalents (MMEs);
- Number/rate of individuals with an average daily MME of more than 50, 90 or 120;
- Number/rate of individuals with overlapping opioid/benzodiazepine prescriptions; and
- Number/rate of individuals with more than 30 days of overlapping opioid/benzodiazepine prescriptions.

Similarly, Illinois tracks a “high-risk patient” population using data from its PDMP to better understand trends among individuals who have been:

- Prescribed both opioids and benzodiazepines;
- Individuals prescribed greater than 90 MME; and

- By number of total prescriptions.

Refine prescribing guidelines: States have significant leverage to implement opioid prescribing guidelines in their Medicaid programs and can then use this claims data to support these interventions. Using PDMP and Medicaid service utilization data, state Medicaid agencies can enact and support policies that reduce opioid prescribing and incentivize non-narcotic pain management. Policymakers in Virginia reviewed both opioid and non-opioid prescribing claims in Medicaid, and found the data suggested opioid prescriptions were the default for pain management. Working with stakeholders, including managed care pharmacy directors, the state removed prior authorization for non-opioid pain management and implemented limitations on opioid prescribing among Medicaid providers. Other states, including Ohio, have similarly used PDMP data to track and manage opioid prescribing limits that reduce the availability of pills for potential diversion. Ohio experienced a 41 percent decrease in opioid doses and a 37 percent decrease in prescriptions between 2012 and 2018 as a result of adopting these kinds of regulations.

Understand substance use trends: Massachusetts analyzed death records, state toxicology reports, and prescribing data from its PDMP to better understand substances involved in the state’s overdose deaths. Matching and analyzing these data sets revealed that people dying from overdose were much more likely to have an illegal substance in their system at the time of death, which resulted in a state review of its harm reduction strategy. The report noted that “(a)s a result of these findings, increasing the availability of harm reduction strategies and interventions that target heroin, fentanyl, and polysubstance use (especially benzodiazepine and cocaine use) could significantly reduce the opioid-related death rate.”

Preventing Overdose and SUD-Related Comorbidities Use Cases

Harm reduction interventions can lower the likelihood of both overdose and infectious disease by engaging individuals in active use to mitigate their risks. State-level data sets can help illuminate state- and community-specific needs related to reducing harm from opioid use, and can identify areas for policy intervention that can both improve outcomes for people using drugs and avoid costs related to chronic, comorbid illnesses.

Target resources where most needed: Targeted deployment of key harm reduction resources, such as naloxone, can be difficult to pinpoint:

- Lay use of naloxone goes unreported, and
- Emergency medical services (EMS) may use multiple doses for one overdose or may use naloxone when overdose is suspected but not present.

Wisconsin took a comprehensive approach in its harm reduction analysis. Policymakers analyzed four indicators across the state to identify areas of greatest need of harm reduction interventions:

Incidents of opioid overdose deaths;

- Opioid overdose hospitalizations;
- Suspected opioid overdose ambulance runs; and
- Newly reported cases of hepatitis C in people age 15 to 29.

The state then used data on available resources, such as syringe services programs, naloxone availability at pharmacies through a standing order, medication-assisted treatment, HIV prevention, hepatitis C treatment, and SUD treatment providers to identify areas experiencing acute gaps in harm reduction resources.

To further support harm reduction efforts, Wisconsin also tracks suspected overdose deaths on a monthly basis, enabling the state to provide more timely and actionable data to state and local officials. The state reviews 911 ambulance runs and uses word searches in free-text fields to identify additional details. Data is presented as unconfirmed.

Push out actionable data to clinicians to treat common comorbidities: The Louisiana Public Health Information Exchange (LaPHIE) was first implemented in 2008 as a partnership between its Office of Public Health and Louisiana State University Health Care Services Division. The OPH maintains comprehensive HIV surveillance data that is updated daily through lab reporting. If a patient enters a participating hospital and a provider opens that patient’s electronic medical record to provide services, the provider will be notified if the patient has not received timely HIV care and prompted to take appropriate action. LaPHIE is bi-directional, any action taken by the provider with respect to the patient, whether it be a referral or a link back into care, is incorporated into the patient’s electronic medical record (EMR) and returned to the OPH, which then updates the state’s HIV surveillance data.

Identify critical intervention points: Several states have used comprehensive, cross-agency strategies to identify patterns and opportunities for intervention, and the Delaware Drug Overdose Mortality Surveillance report is one such example. This report uses data to illuminate the experiences of individuals in the months prior to their deaths and includes information from a broad scope of data sets, including hospital and health system interactions (including EMS and emergency department visits for overdoses), corrections engagement, and interface with the behavioral health system. By looking at non-fatal overdoses and interactions with EMS, officials can understand the systemic interplay and individual experiences of individuals who fatally overdose in order to better target opportunities for intervention, including treatment in emergency departments.

Similarly, in Massachusetts, the state linked ambulance data with state hospital data to identify individuals who had experienced a non-fatal overdose. By leveraging access to data afforded by the state’s opioid data-sharing initiative, Chapter 55, analysts were able to:

- Link information about this subset of individuals to other state data systems;
- Identify individuals’ prescription drug patterns through the state PDMP;
- Chart their contact with the health care and behavioral health systems through the state’s APCD; and
- Document their involvement with corrections.

The state used this information to identify opportunities for intervention and outreach on SUD treatment. A similar data exercise in West Virginia identified that 81percent of those who died from overdoses had interacted with at least one of the state’s health care systems.

Improving Treatment and Recovery Supports Data Use Cases

Ensuring an adequate treatment infrastructure is a high priority as states work to develop access to evidence-based services in the face of this epidemic. By investigating the current treatment landscape in a given state or region, policymakers can analyze unmet need and address gaps in care. Understanding the actual inventory of existing treatment providers through various data sources can help states develop gap analyses and understand workforce needs.

Quantify and optimize current capacity: The Substance Abuse and Mental Health Services Administration (SAMHSA) established a public list of buprenorphine-waivered providers by state and a list of opioid treatment programs (OTP) that provide methadone, also searchable by state. These are helpful starting points when assessing state and local needs, but can be misleading as only a small percentage of waived providers deliver care to the full extent enabled by the waiver process, and providers can choose to opt out of the listing. Policymakers can compare state-level claims data (Medicaid, APCD) to identify waived providers who are not providing treatment or maximizing waiver treatment capacity limits. Through this additional step in analysis, state and local policymakers can drill down to better understand which providers may need support in engaging in the medication for opioid use disorder (OUD) provision. Referring these prescribers to tools such as the SAMHSA Provider Clinical Support System can provide additional tools and supports for those providers who are reluctant to maximize their capacity.

Indiana used state workforce survey data to identify which regions of the state lacked a sufficient amount of SUD treatment providers. The Indiana State Department of Health was one of several funders that supported the development of a user-friendly Health Workforce Information Portal that allows members of the public to create maps and reports to review both current workforce and educational pipelines for emerging professionals. Based on survey data, state, county, and local leaders could identify the number of full-time equivalents across areas of the state for a range of professionals, including psychiatrists, clinical social workers, and addiction counselors.

Understand cost and utilization patterns within Medicaid: Looking at existing cost drivers of SUD in Medicaid claims and encounter data within a state's Medicaid Management Information System (MMIS) can be a helpful starting point for states seeking opportunities to both reduce costs and realign reimbursement structures with service needs. Creating service delivery systems that prioritize a continuum of care in which services can be provided in community clinical settings presents an opportunity for Medicaid programs to reduce costs. In order to better coordinate care and potentially realize cost savings, states can use their Medicaid cost data to develop a range of options that support behavioral and physical health integration and promote team-based care. Virginia's Addiction and Recovery Treatment Services (ARTS) waiver aligned SUD services to the American Society of Addiction Medicine's (ASAM) criteria, and encouraged those services to be provided in primary care settings and office-based outpatient treatment facilities. In doing so, Virginia Medicaid experienced a 32 percent reduction in emergency department visits related to OUD during the second year of the program.

Support real-time access to treatment: In addition to the SAMHSA provider locator mentioned above, states can use self-reported provider data to maintain their own state-level treatment locators, and those can include a range of filters to identify particular information, similar to the tool developed by Kentucky using federal grant funding. Through a diverse partnership, the Kentucky Department for Public Health (via the Kentucky Injury Prevention and Research Center) engaged with the Kentucky Office of Drug Control Policy, the Kentucky Department for Behavioral Health, Intellectual, and Developmental Disabilities, and Operation Unite to pull together provider data and develop a short screening that could connect the user to an available treatment provider. Providers have the necessary access and ability to update their facilities' information daily, and are encouraged to do so. Some states are also employing “bed registries,” tools that track availability of inpatient hospital services, many of which are specific to detox and/or treatment and may serve to help providers in accessing real-time data about available treatment space.

Data Use Cases for At-risk and Underserved Populations

States can also analyze Medicaid service utilization data for specific populations or eligibility categories in order to tailor policy approaches to support vulnerable or underserved populations.

Racial and ethnic disparities: West Virginia, Minnesota, and other states that have analyzed overdose deaths through a racial/ethnic disparity lens have found higher rates of death from overdose among these populations. Minnesota released data analysis focused on the racial disparities it found by reviewing state death certificates and coroners' reports. The state concluded that the overall low drug mortality rate masked significant racial disparities: Blacks were twice as likely to die from a drug overdose than Whites and American Indians were almost six-times more likely to die of a drug overdose than Whites. While drug overdose mortality rates increased for all groups, racial disparities in overdose mortality also increased.

Pregnant women: Through collaborative efforts across state and private agencies, West Virginia identified and addressed a surge in neonatal abstinence syndrome (NAS) and developed a programmatic response. The effort began by standardizing definitions for neonatal withdrawal and providing guidance to clinicians explaining how to use and track diagnostic criteria. The data informed the development of DrugFree Moms and Babies, a program that provides early intervention, treatment, and recovery supports to women and their newborns. The program has improved identification of families at risk and created a structure to support them.

Individuals with corrections involvement: The SUD crisis has highlighted the need for cross-system collaboration between health, behavioral health, and criminal justice systems. A 2017 Special Report from the Bureau of Justice Statistics detailed substance use patterns among individuals incarcerated in state prisons and jails between 2007-2009 and indicated that more than half of incarcerated individuals meet criteria for SUD. Kentucky's Office of Drug Control Policy, in conjunction with the Kentucky Agency for Substance Abuse Policy, publishes a combined annual report that helps policy makers drill down to specific trends or patterns in charges that may indicate SUD, which can then be used to target the development of incarceration-based treatment programs and pre-arrest diversion programs such as the Law Enforcement Assisted Diversion (LEAD) initiative in Louisville. In Massachusetts, the state

Department of Corrections and county-level corrections agencies provided a complete list of people who had been released during one analysis period. The state found that people recently released from corrections facilities were 56-times more likely to die of an opioid overdose than the general public. Moreover, data indicated that those who had received treatment while incarcerated did not have a significant reduction in their risk of overdose. The analysis noted that additional attention should be paid to be individuals leaving corrections facilities, and that treatment should be standardized, regardless of setting.

Individuals without stable housing: Data on housing and homelessness is collected and maintained in Homeless Management Information Systems (HMIS) and can often be accessed directly from the Communities of Care (CoC) that operate regionally to provide a host of services that support housing. CoCs collect and report both housing inventory count (HIC) and point-in-time (PIT) counts of individuals who are homeless, information that can also be accessed at the CoC and state levels through the federal Housing and Urban Development Exchange website. Matching HMIS data with Medicaid utilization data through a state's MMIS can provide opportunities to develop specific interventions for individuals who are homeless and have received services related to SUD. In Connecticut, the state matched HMIS and Medicaid data and identified a subset of Medicaid enrollees with complex and high-cost health care needs. The state used this data to develop program strategies to better support these individuals, and has since documented improved housing retention, decreased use of emergency departments, and improved connection to preventative services.

Supporting recovery: States are increasingly building peer supports into the continuum of care for SUD. While definitions and services provided vary, 39 states currently reimburse for peers in some capacity through their state Medicaid programs. North Carolina, in addition to tracking access data such as buprenorphine prescriptions and enrollment in opioid treatment programs, also includes access to peer recovery as a key metric on that state's opioid dashboard. The state has demonstrated a significant increase in the number of certified peer support providers in the state, and provides the data by county.

Best Practices in Using Data to Support State and Local Policy Development

Comprehensive data – often gathered from across state, local, and federal resources – enables state and local leaders to tailor their prevention, treatment, and recovery responses and make the most of scarce resources. However, effectively using available data, matching or comparing complementary data sets, and identifying what should be the focus of analyses can be complicated. The following are key considerations for states seeking to improve data quality, explore data-sharing opportunities, and analyze existing data sets across systems.

Leadership is critical: Sharing data across state silos is challenging – many agencies generally prefer not to release data. Encouraging the sharing of health care and related data sets requires unifying leadership and a vision that can maintain momentum through many programmatic, legal, and technical hurdles. In some states, such as Pennsylvania, the governor used a disaster declaration to bring agencies to the table to create and sustain that state's multi-agency data capacity. Other states, such as Massachusetts, made significant progress in cross-agency data

sharing through legislation. That state's Chapter 55 public law, passed in 2015, provided the impetus and structure needed for that state's many SUD data innovations.

Engage both technical and policy expertise to make the most of existing data: While technical expertise in essential, policy and programmatic expertise is also a critical factor in successfully using data to support SUD prevention, treatment, and recovery. Data insights help state policymakers understand and explain variances in eligibility groups, interactions between specialty programs, and flag anomalies in the data due to program idiosyncrasies. Data also helps guide analysts in shaping metrics that will have value for policy decision-making.

Allow time and resources to address data governance: How substance use data is stored and shared is covered by both the Health Insurance Portability and Accountability Act (HIPAA) and 42 CFR Part 2 – the latter is specific to SUD data and imposes privacy standards that are often more stringent than those found in HIPAA. With few exceptions, providers and stewards of SUD data must obtain consent before sharing personally identifiable information that is protected by 42 CR Part 2. States can make the most of sharing data across agencies by building in time and resources to manage data governance issues:

- Data use agreements help to clearly articulate how organizations will use data, and specifically how it supports policy development. This Centers for Medicare & Medicaid Services fact sheet on DUAs outlines necessary components, helpful tips, and includes state example documents. Recognizing the limitations of all data sets included in a DUA also helps to expedite work. Confidentiality issues can be addressed clearly and completely, eliminating onerous approaches to de-identification or aggregation that may not ultimately be necessary. State agencies may have existing DUAs in place that can support new/emerging uses.
- Massachusetts was able to combine protected data from across ten disparate state agencies through a project-specific de-identification process that assigned random identifiers to each record. The state also developed a series of legal agreements that covered how data would be linked, shared, hosted, and accessed.

Expect challenges:

- **Timeliness** of data in a rapidly shifting substance use epidemic can be a challenge for virtually all data sets, as very few reporting systems offer real-time data. Longer lags, however, particularly those that pass more than a year from collecting data to reporting, make some data sets better used for understanding the landscape in retrospect rather than as a planning tool. Some states use unconfirmed data when necessary to track particularly urgent indicators, such as drug overdose deaths.
- **Completeness of data sets** – and the lack thereof – can also pose limitations for policymakers and is a major factor in data quality. State Medicaid enrollees, for instance, may move on and off the program as individual eligibility fluctuates, creating gaps in coverage and in key data points, such as current addresses. Encounter data from Medicaid managed care plans can also be problematic – states can improve encounter data quality through contract incentives, regular communication, and guidance. State-level guidance to providers and/or managed care organizations may be required to improve completeness of data.

Conclusion

Many data sets produced by state and federal agencies have value when used individually, but when data can be shared and presented in new ways, it begins to tell a more comprehensive story of the particular and highly localized impact of SUD across systems and populations. There has been unprecedented activity at the state level in recent years to identify and use data sources to better understand and address state and local needs to prevent SUD, reduce the harms caused by SUD, and promote treatment and recovery. While states adopt indicators and metrics that meet specific state needs, there is an increasingly innovative menu of options to support their efforts.

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